



Fiscal Year
2014
Annual Report

National Center on Birth Defects and Developmental Disabilities

*Promoting the health
of babies, children,
and adults throughout
the lifespan.*



National Center on Birth Defects and Developmental Disabilities
Office of the Director



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Message from the Director

These are very exciting and busy times at the National Center on Birth Defects and Developmental Disabilities (NCBDDD). In preparation for this, our 6th Annual Report, we reflect on the wonderful work of the Center and recognize our many outstanding accomplishments and achievements.

NCBDDD continues to do wonderful work making a difference across the lifespan, which is evidenced through the execution of our four focus areas:

- Saving Babies Through Birth Defects Prevention and Research
- Helping Children Live to the Fullest by Understanding Developmental Disabilities like Autism
- Protecting People and Preventing Complications of Blood Disorders, and
- Improving Health of People with Disabilities



These focus areas exemplify the sustained need to protect those who are vulnerable to health risks, such as babies, children, people with blood disorders, and people with disabilities. And this year, to further our focus area work, we have increased our efforts to advance the NCBDDD's public health impact by promoting three key action areas, uniquely known as *Strategic Health Initiatives*: Safer Medication Use in Pregnancy, Preventing Health Care Associated Venous Thromboembolism (VTE), and Aligning Practice with Treatment Guidelines for Attention-Deficit/Hyperactivity Disorder (ADHD) in Young Children.

Each initiative represents the melding of public health and health care with a goal of improving health of at risk populations through evidence-informed/based health care.

The strategic health initiatives serve to catalyze medical and professional organizations, health care systems, federal agencies, and public and private sector organizations toward action-- and this work is only just beginning.

Prevention is key and the heartbeat of our initiatives. We know that many doctors and women face uncertainty about using medication during pregnancy. Safer medication use in pregnancy will lead to healthier pregnancies and healthier babies through better research, reliable guidance, and informed decisions. We know that 70% of health care associated VTEs are preventable and that evidence based interventions will reduce the number of post-surgical patients who die from blood clots. We also know that experts agree families of young children with ADHD should be referred to behavioral therapy as first-line treatment. Realignment of current practices will, lead to more U.S. children who grow healthy, reach their full potential, and live a productive adult life.

I am deeply grateful to our dynamic staff members who are passionate about making a difference in the lives of individuals and families living with birth defects, blood disorders, or disabilities; these remarkable individuals offer direction to the Center, many of whom are guided by their own life experiences. With that passion, we will continue to work with our partners and stakeholders to sustain and enhance the impact of our programs and resource base. We have much to be proud of and we will continue to build on this solid foundation to raise achievements in the coming years.

Thank you for your continued efforts and interest in NCBDDD.
Sincerely,



Coleen A. Boyle, PhD, MS(Hyg)
Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD)





Saving Babies through Birth Defects Prevention and Research

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made notable progress in its mission to prevent birth defects in 2014.

Every 4 ½ minutes, a baby is born with a major birth defect in the United States. That's 1 in 33 babies. Birth defects are structural changes in one or more parts of the body that are present at birth. NCBDDD identifies causes of birth defects, finds opportunities to prevent them, and improves the health of those living with birth defects.

By applying a public health approach incorporating three essential elements—surveillance or disease tracking, research to identify causes, and prevention research and programs—we can rapidly translate scientific findings into appropriate public health interventions.



Accomplishments

- Began the next generation of birth defects prevention research with BD-STEPS. Funded six research centers across the United States to collaborate and collect data, starting with children born in 2014. Results will offer more knowledge about modifiable factors that might raise or lower the risk of having a baby with a birth defect.
- Collaborated with federal and external partners to develop a national strategy to improve the health of mothers and babies through better research, reliable guidance, and informed decisions related to safer medication use in pregnancy. Launched a new Treating for Two website which provides valuable resources for women, families, and health professionals and developed an infographic to educate policymakers and partners. Additionally, initiated multiple projects to address knowledge about prenatal exposure to opioids and other commonly used medications.
- Advanced global neural tube defects prevention efforts through Birth Defects COUNT. Collaborated with the World Health Organization and International Clearinghouse for Birth Defects Surveillance and Research to develop birth defects surveillance tools for low-and middle-resource countries. Supported development of country-level birth defects monitoring and prevention strategies in South-East Asia and formed a collaboration to implement a demonstration project to assess folic acid fortification feasibility, sustainability, and health impact in India.
- Achieved significant milestones in our project to estimate the prevalence and understand the health issues of adolescents and adults born with a heart defect, including collecting data and finalizing a plan for analysis.
- Released unique data and created new tools to prevent risky alcohol use for all adults, including pregnant women. Contributed to a CDC Vital Signs report highlighting alcohol screening and brief intervention (SBI) as an effective but underused health service. Addressed this gap with a guide to help primary care practices implement alcohol SBI as a routine part of health care. Also released new, research-based materials to prevent fetal alcohol spectrum disorders.





Looking to the Future

Our ongoing state-based birth defects tracking system and public health research continue to form the scientific foundation for preventing birth defects and helping people thrive throughout their lives. Further strengthening this foundation through enhanced tracking would allow better understanding of the causes of birth defects and the lifelong implications on cost and quality of life. Similarly, our prevention programs seek to translate this knowledge into actionable health promotion programs that change people's lives. Our public health programs continue to show promise and potential to expand and help millions of Americans live healthier lives.

Notable 2014 Scientific Publications

Broussard CS, et al. Developing a systematic approach to safer medication use during pregnancy: Summary of a Centers for Disease Control and Prevention-convened meeting. *Am J Obstet Gynecol*. 2014;211(3):208-214.e1.

Dawson AL, et al; National Birth Defects Prevention Study. Maternal exposure to methotrexate and birth defects: A population-based study. *Am J Med Genet A*. 2014;164(9):2212-6.

Canfield MA, et al. The Association Between Race/Ethnicity and Major Birth Defects in the United States, 1999-2007. *Am J Public Health*. 2014;104(9):e14-e23.

Simeone RM, et al. Pediatric inpatient hospital resource use for congenital heart defects. Birth Defects Res Part A: Clin Mol Teratol. 2014;100(12):934-43.

Honein MA, et al. Prevention of orofacial clefts caused by smoking: implications of the Surgeon General's Report. Birth Defects Res A Clin Mol Teratol. 2014; 100(11):822-5.

Simeone RM, et al. Diabetes and congenital heart defects: a systematic review, meta-analysis, and modeling project. *Am J Prev Med*. 2015; 48(2):195-204.

Tinker SC, et al. Estimate of the potential impact of folic acid fortification of corn masa flour on the prevention of neural tube defects. *Birth Defects Res A Clin Mol Teratol*. 2013;97(10):649-57.

Crider KS, et al. Population red blood cell folate concentrations for prevention of neural tube defects: Bayesian model. *British Medical Journal*. 2014 Jul 29;349:g4554. doi: 10.1136/bmj.g4554.

Qi YP, et al. The prevalence of low serum vitamin B-12 status in the absence of anemia or macrocytosis did not increase among older US adults after mandatory folic acid fortification. *J. Nutr*. 2014;144: 170-176. doi:10.3945/jn.113.183095.

Hutton HE, et al. A novel integration effort to reduce the risk for alcohol-exposed pregnancy among women attending urban STD clinics. *Public Health Reports*. 2014;129(1):56-62.



Spotlight On:

National Birth Defects Prevention Network Parent Advisory Group

When my daughter was born with multiple birth defects, I was scared. I had no idea what challenges she would face. Ashley was born in 2005 with gastroschisis – which meant her intestines protruded from her abdomen and required immediate, life-saving interventions; microtia/atresia – which has left her permanently hearing impaired; and velopharyngeal insufficiency secondary to submucosal cleft – leaving her with a speech impediment. Additionally, she suffers from sensory issues thought to be from her NICU stay. Today, my daughter is 9 years old and is a wondrous testimony to the vibrancy of life. She plays piano, reads voraciously, runs track for the city team, dances ballet/jazz/hip-hop, and engages in regular social justice and community service activities. She is an everyday miracle.

Throughout her lifetime, I have reached out to other families to provide support and have assisted in founding the first nonprofit in the United States for gastroschisis, Avery's Angels Gastroschisis Foundation. In 2011, I became part of the National Birth Defects Prevention Network Parent Advisory Group. Our group started with five parent advocates and our goal was to raise public awareness about birth defects. We created a public service announcement that aired nationally and internationally, assisted the CDC with prevention efforts, and published a peer-reviewed journal article that has been internationally cited. We received a national award for our advocacy efforts. Currently, we are focused on building a non-partisan, parent-driven advocacy group aimed at impacting public policy for those affected by birth defects. Being a part of this group means that I am able to create far-reaching impact from my own experience, and it is my hope that one day everyone in the United States will realize how important it is to fund birth defects surveillance, monitoring, and prevention programs to ensure the health of our children and future generations.

- Kayte Thomas



Helping Children Live to the Fullest by Understanding Developmental Disabilities like Autism

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) released new data showing the estimated number of children with autism spectrum disorder continues to rise and advanced research to help us better understand “why”.

More children than ever before are being diagnosed with autism spectrum disorder (ASD) making ASD an important public health concern. ASD is a developmental disability that is related to differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. NCBDDD works to provide essential data on ASD, search for risk factors and causes of ASD, and develop resources that help identify children with ASD and other developmental disabilities as early as possible.



Accomplishments

- Shared new prevalence estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network indicating that about 1 in 68 eight-year-old children living in multiple communities in 2010 were identified with ASD. These new data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children with ASD and their families receive the help they need.
- Promoted developmental monitoring and screening to help children with developmental delays be identified as early as possible. “Learn the Signs. Act Early” partnered with the HHS/Department of Education initiative, Birth to 5: Watch Me Thrive!, that reached federal grantees and partners in health care and child care, families, and communities across the country. Its newest tool, Watch Me! Celebrating Milestones and Sharing Concerns, is dynamic, interactive continuing education training for child care providers and teachers.
- Demonstrated the potential impact of new diagnostic criteria for ASD. Released findings from the first population-based study that suggest estimates of the number of children with ASD might be lower using the current *DSM-5* criteria than using the previous *DSM-IV-TR* criteria.
- Supported champions in communities across the United States to raise awareness of ASD and take action to help children. Disseminated an updated ADDM Network Community Report and state-specific “one-pagers”. These tools offer basic information on ASD in the country and in each ADDM community, including general prevalence, differences by sex, race/ethnicity, and average age of diagnosis.
- Responded to community concerns about the number of Somali children with ASD in Minneapolis by helping the University of Minnesota implement CDC’s rigorous ASD tracking method. The project findings are currently being used by community stakeholders to make improvements in the hopes that *all* children in Minneapolis are identified and connected to services and supports as soon as possible.



Looking to the Future

By working with partners across the country, NCBDDD is embedding early screening at unprecedented levels across the spectrum of services available to families and children. This action complements our research to help answer the question, “How many children have ASD?” and to document the rising rate of ASD. Our newest research expands to dive into the question of, “Why?” NCBDDD strives to discover more detailed answers to “why” and “how many,” for both children and adults. This can be accomplished by expanding our monitoring and tracking to include adolescents and adults, building our capacity beyond the ADDM network, and investigating faster and more accurate methods. Ultimately, this work allows CDC and countless organizations to better serve children and adults with ASD.

Notable 2014 Scientific Publications

CDC. Prevalence of autism spectrum disorder among children aged 8 years-Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveill Summ.* 2014 Mar 28;63(2):1-21.

Bakian AV, et al. Brief Report: Independent validation of autism spectrum disorder case status in the Utah Autism and Developmental Disabilities Monitoring (ADDM) Network Site. *J Autism Dev Disord.* 2014 Jul.

Christensen DL, et al. Socioeconomic status, child enrichment factors, and cognitive performance among preschool-age children: results from the Follow-Up of Growth and Development Experiences Study. *Res Dev Disabil.* 2014 Jul;35(7):1789-801.

Johnson NL, et al. Genomics and Autism Spectrum Disorder. *J Nurs Scholarsh.* 2013 Mar;45(1):69-78. doi: 10.1111/j.1547-5069.2012.01483.x. Epub 2013 Jan 31.

Maenner MJ, et al. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry.* 2014 Mar;71(3):292-300.

Miller JE, et al. Maternal infections during pregnancy and cerebral palsy: a population-based cohort study. *Paediatr Perinat Epidemiol.* 2013 Nov;27(6):542-52.

Phillips KL, et al. Prevalence and impact of unhealthy weight in a national sample of US adolescents with autism and other learning and behavioral disabilities. *Matern Child Health J.* 2014 Oct;18(8):1964-75.

Rice CE, et al. Screening for developmental delays among young children--National Survey of Children's Health, United States, 2007. *MMWR Surveill Summ.* 2014 Sep 12;63:27-35.

Rubenstein E, Wiggins LD, Lee LC. A review of the differences in developmental, psychiatric, and medical endophenotypes between males and females with autism spectrum disorder. *J Dev Phys Disabilities.* 2014 Aug [epub ahead of print].

Schieve LA, et al. Population attributable fractions for three perinatal risk factors for autism spectrum disorders, 2002 and 2008 Autism and Developmental Disabilities Monitoring (ADDM) Network. *Ann Epidemiol.* 2014 Apr;24(4):260-6.



Spotlight On: Association of University Centers on Disabilities

I think about my aunt often when I work with the Act Early Ambassadors and my colleagues at the Association of University Centers on Disabilities (AUCD). My aunt noticed that her son Christopher was not doing things like his older sisters. He avoided others, but he was talking and remembered stories by heart. When Christopher was about three, he was diagnosed with autism. So I was excited to have the opportunity to lead AUCD's collaboration on the pilot program of the Act Early Ambassador project (2010-2011), with ten state-level Ambassadors working to support systems for early identification of developmental delay to serve as liaisons to the national "Learn the Signs. Act Early." Campaign.

In 2014, the Ambassadors expanded to 29 states and one organization. It is rewarding to be part of the Ambassador project as I get to help develop a national network of state-level experts to improve early identification practices, as well as collaborate with campaign partners like the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). Ambassadors work as community champions with programs that serve young children and their parents, as well as health care and child care professionals to improve early identification of developmental delay. Ambassadors collaborate with state agencies and campaign partners to improve policy and programs for early identification. I have been fortunate to be able to apply the principles of action learning that I have gained through my DrPH studies at the University of Illinois at Chicago with small group examination of early identification issues and sharing of lessons learned across states so that other Ambassadors may benefit from these learnings. It is my hope that someday each state will have an Ambassador to connect parents like my aunt with vital information on childhood developmental milestones and steps to take about any concerns.

Adriane Griffen





Protecting People and Preventing Complications of Blood Disorders

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made significant progress in its efforts to improve the lives of people with blood disorders in 2014.

Blood disorders - such as deep vein thrombosis, hemophilia, and thalassemia - affect millions of people each year. Men, women, and children of all backgrounds live with the complications of these conditions, many of which are painful and potentially life-threatening. NCBDDD works to reduce the public health burden of blood disorders by contributing to a better understanding of blood disorders and their complications; developing, implementing and evaluating prevention programs; providing information to consumers and health professionals; and encouraging action to improve the quality of life for people living with these conditions.



Accomplishments

- Highlighted NCBDDD's role in meeting the emerging public health needs of people with blood disorders in the September 20, 2014 issue of the American Journal of Preventive Medicine. Five papers addressed CDC's efforts to strengthen surveillance activities for blood disorders and expand partnerships to provide a better understanding of the health status, needs, economic burden and health-related quality of life of people with nonmalignant blood disorders.
- Launched a "Webinar Series on Bleeding and Clotting Disorders" to provide evidence-based information on new research, interventions, emerging issues of interest in blood disorders, as well as innovative approaches in collaborations and partnerships.
- Launched a website on Vitamin K Deficiency Bleeding that includes fact sheets, frequently asked questions, articles, videos, podcasts, and personal stories to increase parent and provider understanding of the importance of vitamin K shots for newborns.
- Published a new surveillance report to disseminate the information collected by the Universal Data Collection system during the years 2005 through 2009. The report contains information about the demographic characteristics of the participants, their blood and factor product use, and the occurrence and treatment of joint and infectious diseases.
- Published the results of a six-year study, called the Hemophilia Inhibitor Research Study (HIRS), which was designed to test the feasibility of conducting national monitoring for inhibitors among people with hemophilia in the United States. Key findings were summarized and posted to the web.
- Published an article that describes the efforts of the states participating in the Registry and Surveillance System for Hemoglobinopathies (RuSH) and federal agencies to design the project and the methods used to collect data for the system. The key findings were summarized on the web.





Looking to the Future

CDC will improve the understanding of complications of blood transfusions used to treat people with thalassemia and sickle cell disease, as well as the causes and risk factors for developing inhibitors in people with hemophilia. We will evaluate and promote the use of periodic inhibitor screening, monitor complications from blood and treatment products, and assess the effectiveness of prevention strategies. We remain focused on healthcare-associated VTE prevention; improving laboratory techniques; and increasing provider and public knowledge and awareness of the signs and symptoms of blood disorders, the importance of early recognition and diagnosis, and referrals to specialists and comprehensive care.

Notable 2014 Scientific Publications

Soucie JM, et al. A study of prospective surveillance for inhibitors among persons with haemophilia in the United States. *Haemophilia*. 2014;20:230-7.

Skinner MW, et al. The national haemophilia program standards, evaluation and oversight systems in the United States of America. *Blood Transfus*. 2014;12 Suppl 3:s542-8.

Sidonio RF, et al. and the HTCN. Females with FVIII and FIX deficiency have reduced joint range of motion. *Am J Hematol*. 2014;89:831–836.

Payne AB, et al. High factor VIII, von Willebrand factor, and fibrinogen levels and risk of venous thromboembolism in blacks and whites. *Ethn Dis*. 2014 Spring;24(2):169-74.

Miller CH, et al. Gender, race and diet affect platelet function tests in normal subjects, contributing to a high rate of abnormal results. *Br J Haematol*. 2014 Jun;165(6):842-53.

Streiff MB, et al. CDC Grand Rounds: preventing hospital-associated venous thromboembolism. *MMWR Morb Mortal Wkly Rep*. 2014 Mar 7;63(9):190-3.

Yusuf HR, et al. Risk of venous thromboembolism among hospitalizations of adults with selected autoimmune diseases. *J Thromb Thrombolysis*. 2014 Oct;38(3):306-13.

Rhynders PA, et al. Providing Young Women with Credible Health Information about Bleeding Disorders. *Am J Prev Med*. 2014 Sep 9. pii: S0749-3797(14)00407-3.

Hulihan MM, et al. State-based surveillance for selected hemoglobinopathies. *Genet Med*. 2014 Jul 3. doi:10.1038/gim.2014.81.

Mainous AG 3rd, et al. Elevated transferrin saturation, health-related quality of life and telomere length. *Biometals*. 2014 Feb;27(1):135-41.



Spotlight On: Hemophilia Federation of America

Hemophilia Federation of America (HFA) is a national grassroots community organization that was formed in 1994 to assist all people living with a bleeding disorder. HFA provides programing and advocacy support for those with bleeding disorders to encourage community members to lead healthy and active lifestyles and have access to the care they need to manage their condition. The needs of the community are incredibly unique which is why having strong advocates, to ensure access to life-saving medication and healthcare providers, is crucial.

Growing up, my brother had hemophilia and I have two cousins that are also affected by the condition. While very familiar with the particular needs of the community, I had been away from it for some time. Since starting at HFA over a year ago, I have found an area where I can use my government relations and advocacy experience for something I am passionate about. HFA delivers programs that help adult men cope with their bleeding disorders, moms and dads become more involved in their child's healthcare, and give women a much needed voice. I have helped to develop an app that speaks specifically to the needs of women with bleeding disorders, allowing them to track their menstrual cycles and bleeds. From an advocacy perspective, my work here has allowed me to fight for legislation to keep medication affordable both federally and in the states; to help educate payers on the specific needs of the community; and overall ensure that the community has the care they need. I've been able to help individuals solve specific problems with discrimination and denial of care. I feel fortunate to be a part of such a successful group of advocates and look forward to continuing HFA's mission of supporting the community.

- Katie Verb



Improving the Health of People with Disabilities

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) made a difference in the nationwide effort to reduce health disparities among people with disabilities.

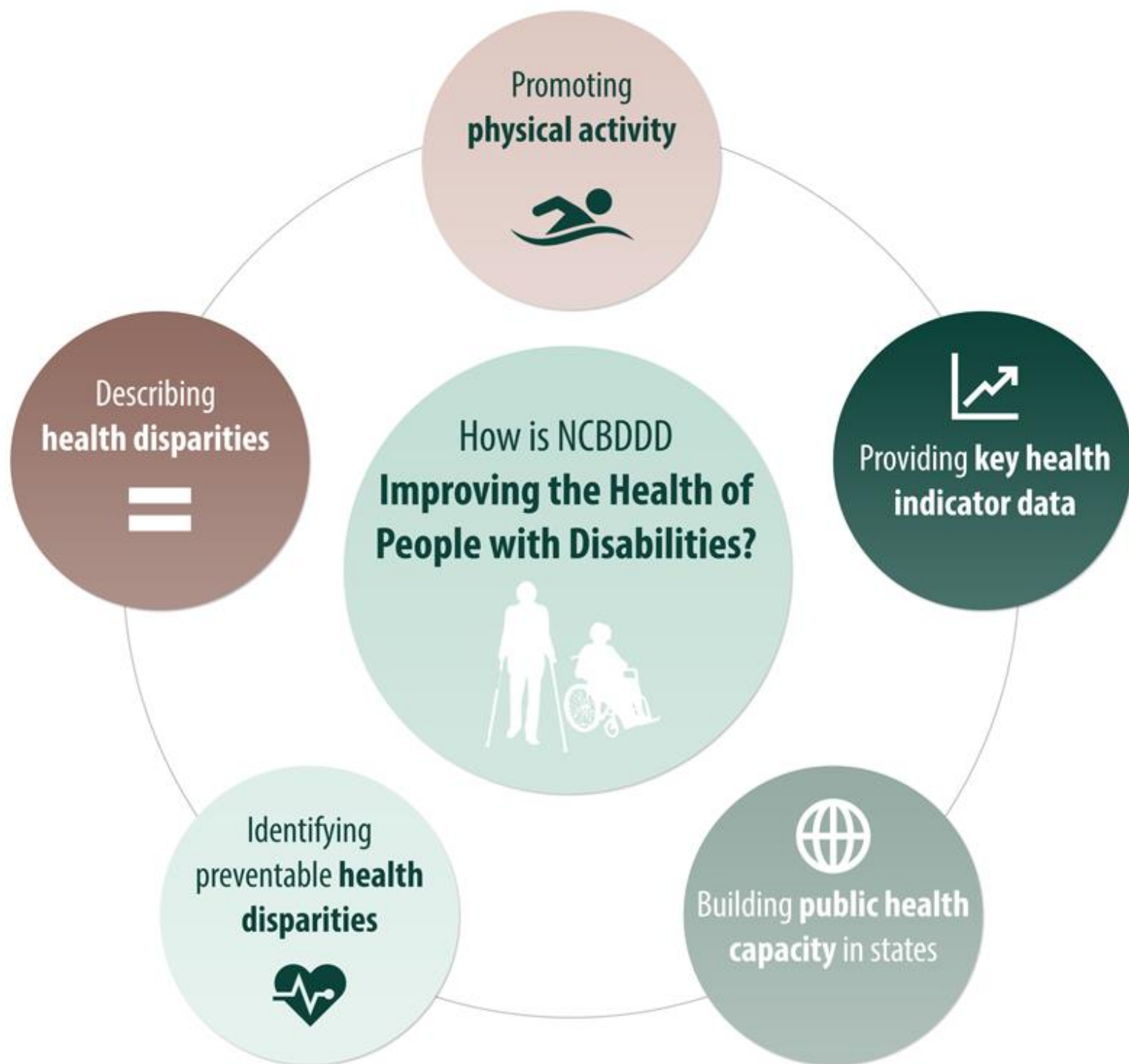
In the United States, an estimated 39 million to 57 million people live with a disability. At NCBDDD, we define disability as a long-term or permanent limitation in movement, cognition, vision, or hearing. We work to promote the health of people living with disabilities so they can live, work, and play in their communities. Through public health efforts, such as tracking, research, and health communication and education, we aim to reduce health disparities and the incidence as well as the severity of additional physical or mental health conditions that occur as a result of having a disability.



Accomplishments

- Launched a nationwide report on adults with disabilities and physical activity. CDC's Vital Signs™: "Adults with Disabilities – Physical Activity is for Everybody" presented data showing that 1 in 2 adults (18-64 years of age) with a disability get no aerobic physical activity and that people with disabilities who had a recommendation from a doctor or health professional were more likely to be physically active. Materials and messages, including a website dedicated to resources for doctors and health professionals, were delivered to over 140 partner organizations and reached an estimated 138 million people.
- Updated Disability and Health Data System (DHDS) to include the latest data from the 2012 Behavioral Risk Factor Surveillance System on key health indicators and provide new ways to see data. DHDS continues to be the only state-level disability and health data system that helps national and state organizations identify opportunities to improve the health of people with disabilities by using data to build partnerships with programs.
- Increased public health capacity in 18 states using the Disability and Health Network to plan, prepare and include people with disabilities in health-protecting programs and services. The majority of these states have identified policy needs within their state; worked to increase the number of facilities providing preventive healthcare screenings; and assessed state emergency plans – all to better include, provide access to, and ultimately improve the health of, people with disabilities.
- Published an important scientific article, which documented for the first time that adults with specific types of disabilities are more likely to have measured high blood pressure compared with adults without disabilities. A key findings web page was developed and was promoted to thousands of people and organizations in conjunction with the Million Hearts Program.





Looking to the Future

Disability is part of the typical human experience and is often perceived as poor health. Our work, with sustained support, can change that perception. NCBDDD is committed to protecting the health of people with disabilities across their lifespan by integrating CDC's public health science with national and state disability and health programs.

We will continue to help reduce health disparities of people with disabilities by including them in public health surveys, public health programs, emergency preparedness and planning efforts, and accessible healthcare services. We will continue to support state-based programs, which promote healthy lifestyles and improve the quality of life for people with disabilities. Our collaboration with national partners will continue to improve the health of people with disabilities by increasing access to health care services and implementing programs, while also providing health education to promote health, wellness, and the adoption of healthy behaviors for people with disabilities.

Notable 2014 Scientific Publications

Anderson WL, et al. Obesity and people with disabilities: The implications for health care expenditures. *Obesity*. 21: E798–E804. doi: 10.1002/oby.20531.

Bayliss EA, et al. Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters. *American Family Medicine*. 2014;May-Jun;12(3):260-269.

Carroll DD, et al. Vital signs: disability and physical activity - United States, 2009-2012. *MMWR Morb Mortal Wkly Rep*. May 9 2014;63(18):407-413.

Courtney-Long E, et al. Disparities in current cigarette smoking prevalence by type of disability, 2009-2011. *Public Health Rep*. 2014 May;129(3):252-60.

Kim S, et al. Metabolic risk factors in U.S. youth with low relative muscle mass. *Obesity Research & Clinical Practice*. Published online: June 17, 2014

Krahn G, et al. Health Disparities of Adults with Intellectual Disabilities: What Do We Know? What Do We Do? *Journal of Applied Research in Intellectual Disabilities*. 2014;Sep; 27(5):431-446.

Ouyang L, et al. Characteristics and survival of end stage renal disease (ESRD) patients with spina bifida in the United States Renal Data System (USRDS). *The Journal of Urology*. 2014 Aug 25. doi: 10.1016/j.juro.2014.08.092.

Ouyang L, et al. A comparison of family financial and employment impacts of fragile X syndrome, autism spectrum disorders, and intellectual disability *Research in Developmental Disabilities*. 2014;Jul;35(7):1518-1527.

Stevens A, et al. Hypertension Among US Adults by Disability Status and Type, National Health and Nutrition Examination Survey, 2001–2010. *Prev Chronic Dis*. 2014;11:140162.

Visser SN, et al. Trends in the Parent-Report of Health Care Provider-Diagnosed and Medicated Attention-Deficit/Hyperactivity Disorder: United States, 2003–2011. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2014;53(1):34-46.e32.



Spotlight On: Spina Bifida Association

The Spina Bifida Association (SBA) is the only national organization in the United States that works on prevention of spina bifida while supporting those people affected by the birth defect and its complicated conditions. SBA has partnered with NCBDDD for a decade to improve the health of people with spina bifida. In fact, no other organization or governmental entity is working on improving the health of people with spina bifida—both young and old!

In conjunction with NCBDDD, we are working to create a Spina Bifida Collaborative Care Network (SBCCN). When the SBCCN is fully functioning it will identify and facilitate the provision of expert clinical care and necessary educational resources for people living with spina bifida in order to improve their health, function, and participation in their healthcare.

Some activities of the SBCCN will be to:

- Monitor, track and evaluate care provided in spina bifida clinics,
- Provide input into research priorities for the National Spina Bifida Patient Registry (NSBPR), and
- Monitor and track the implementation of those practices that have had the greatest positive impact on the health of people with spina bifida.

Over the years, SBA has partnered with NCBDDD to create a Spina Bifida National Resource Center. Each year, SBA connects with over 1000 families to answer their questions about spina bifida. Sometimes, the question may be from a mother who has just found out that her child is going to be born with spina bifida while others are from adults with spina bifida looking to find a physician who can treat them. Other questions are from caregivers looking for funds to buy catheters for their children or from adults with very serious health conditions with no physicians to treat them. NCBDDD has helped SBA to find answers to these questions and on some occasions those answers have saved a person's life.

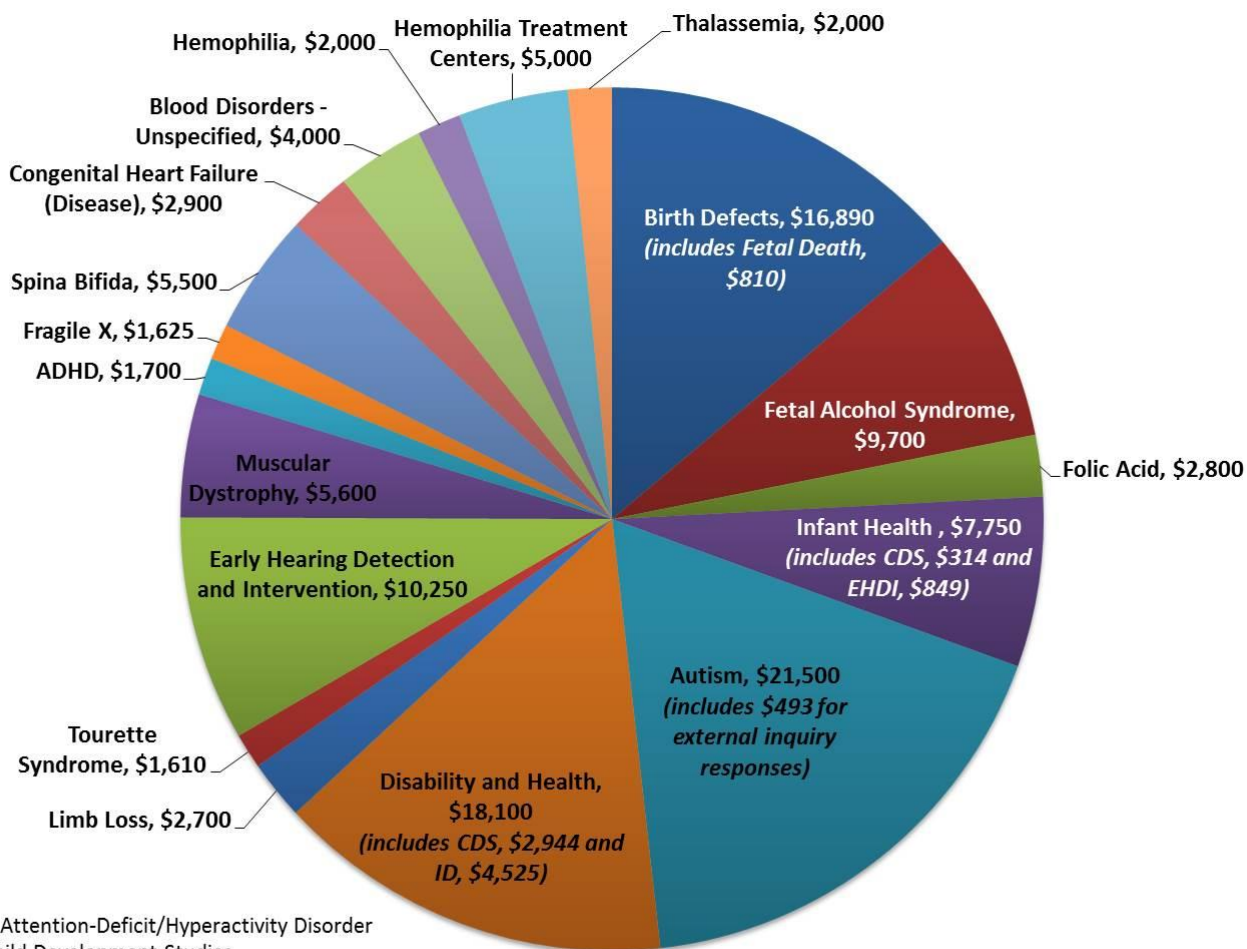
- Sara Struwe



Budget

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) fiscal year (FY) 2014 appropriation includes \$122.435 million for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders.

Funds are currently supporting surveillance, research, and prevention activities that are addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.



ADHD: Attention-Deficit/Hyperactivity Disorder
CDS: Child Development Studies
EHDI: Early Hearing Detection and Intervention
ID: Intellectual Disability

Note: Dollar amounts are in thousands.

**NCBDDD FY 2014 Appropriations
(in thousands)**

Child Health and Development	\$59,450
Birth Defects	\$16,890
<i>Craniofacial Malformation</i>	\$0
<i>Fetal Death</i>	\$810
Fetal Alcohol Syndrome	\$9,700
Folic Acid	\$2,800
Infant Health	\$7,750
<i>Child Development Studies</i>	\$314
<i>Early Hearing Detection and Intervention</i>	\$849
Autism	\$21,500
<i>External Inquiry Responses</i>	\$493
Health and Development w/ Disabilities	\$49,985
Disability and Health	\$ 18,100
<i>Child Development Studies</i>	\$2,944
<i>Intellectual Disability</i>	\$4,525
Limb Loss	\$2,700
Tourette Syndrome	\$ 1,610
Early Hearing Detection and Intervention	\$ 10,250
Muscular Dystrophy	\$ 5,600
Reeve Paralysis Resource Ctr.	\$0
Attention-Deficit/Hyperactivity Disorder	\$ 1,700
Fragile X	\$ 1,625
Spina Bifida	\$ 5,500
Congenital Heart Failure (Disease)	\$2,900
Public Health Approach to Blood Disorders	\$13,000
Blood Disorders - Unspecified	\$4,000
Hemophilia	\$2,000
Hemophilia Treatment Centers	\$5,000
Thalassemia	\$2,000
NCBDDD Total	\$122,435





Select State-Based Activities and Funding

Alabama

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Alabama Department of Public Health (DD11-1101, 000793)
\$146,580

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Alabama, Birmingham (DD10-1002, 000678)
\$143,173

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities
University of Alabama, Birmingham (DD12-1205, 000906)
\$1,000,000

Development and Evaluation of a Clinic-Based Screening and Brief Intervention (SBI) for Changing Behaviors Related to Cytomegalovirus CMV
University of Alabama, Birmingham (DD12-005 000922) *Use of carryover funds

Improving the Health of People with Disabilities through State Based Public Health Programs
Alabama State Department of Public Health (DD12-1204, 000947)
\$300,000

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida
University of Alabama (DD14-002, 001080)
\$59,984

Comp C-Improving the Care and Outcomes of People Living with Spina Bifida
University of Alabama (DD14-002, 001079)
\$19,960

Alaska

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Alaska Department of Health (DD11-1101, 000780)
\$156,933

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Centers
University of Alaska, Anchorage (DD11-1107, 000886)
\$75,000



Improving the Health of People with Disabilities through State Based Public Health Programs
Alaska State Department of Public Health (DD12-1204, 000948)
\$300,000

Arkansas

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Arkansas Department of Health (DD11-1101, 000789)
\$133,024

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Arkansas (DD10-1002, 000679)
\$271,118

Improving the Health of People with Disabilities through State Based Public Health Programs
University of Arkansas (DD12-1204, 000932)
\$299,999

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
Arkansas Children's Hospital Research Institute (DD13-003, 001039)
\$765,000

Arizona

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Arizona Department of Health Services (DD10-1001, 000609)
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Arizona Department of Health Services (DD11-1101, 000826)
\$139,718

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies
University of Arizona (DD11-006, 000830) *Use of carryover funds

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Arizona (DD10-1002, 000680)
\$300,173

California

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II
Kaiser Foundation Hospitals (DD11-002, 000748)
\$1,100,000



Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
California Department of Health Care Services (DD11-1101, 000816)
\$148,800

National Spina Bifida Patient Registry Clinic Demonstration Project
Children's Hospital & Research Center @ Oakland (DD11-001, 000743) **No FY 14 Funds –Ended 8/31/14

National Spina Bifida Registry Longitudinal Data Collection and Evaluation
Children's Hospital Of Los Angeles (DD11-005, 000770) **No FY 14 Funds -Ended 8/29/14

Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded Community Health Centers
AltaMed Health Service Corp (DD10-1006, 000726) **No FY 14 Funds – Ended 8/31/14

Blood Safety Surveillance Among People with Blood Disorders
Children's Hospital Los Angeles (DD11-1108, 000874) **No FY 14 Funds – ended 4/30/14

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Public Health Institute (DD14-1408) - DD12-1206-001008) **No FY 14 Funds – Project ended 9/29/14

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
Stanford University (DD13-003, 001033)
\$745,000

Colorado

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II
University of Colorado Denver (DD11-002, 000750)
\$1,100,000

Population Based Surveillance and Utilization of Surveillance Data by Public Health Departments
Colorado Department of Public Health and Environment (DD10-1001, 000596)
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Colorado Department Of Public Health And Environment (DD11-1101, 000822)
\$149,093

Public Health Research for the Prevention of Complications of Bleeding Disorders
University of Colorado Denver (DD11-009, 000757)
\$189,998

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network
Colorado Department of Public Health and Environment (DD10-1002, 000686)
\$285,393



Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance
Denver Health and Hospital Authority (DD13-1301, 001046)
\$274,898

Comp A-Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
Colorado State Department of Public Health and Environment (DD14-001, 001126)
\$500,000

Comp B-Research Approaches to Improve the Care and Outcomes of People Living with SB
University of Colorado (DD14-002, 001093)
\$60,082

Connecticut

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Connecticut Department of Public Health (DD11-1101, 000817)
\$188,327 (includes: \$170,000 original award with a 10.8% supplement of \$18,327)

Delaware

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Delaware Department of Health and Social Services (DD11-1101, 000819)
\$94,485

Improving the Health of People with Disabilities through State Based Public Health Programs
University of Delaware (DD12-1204, 000953)
\$299,992

Florida

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Florida Department of Health (DD10-1001, 000608)
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Florida Dept of Health (DD11-1101, 000810)
\$124,430

Improving the Health of People with Disabilities through State Based Public Health Programs
Florida State Department of Health (DD12-1204, 000992)
\$300,000



Georgia

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Georgia Dept of Community Health (DD11-1101, 000824)
\$155,536

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Georgia Department of Public Health DD14-1408 (DD12-1206-001010) **No FY 14 Funds – Ended 9/29/14

Characterizing the Complications Associated with Therapeutic Blood Transfusions for Hemoglobinopathies GA
State University (DD14-1406)
\$470,000

Surveillance and Congenital Health Defects (CHDS) focusing on Adolescents and Adults
Emory University (DD12-1207, 001027)
\$425,000

Cooperative Agreement for the Strengthening and the Development of Applied
Task Force for Global Health, Inc. (GH10-1006, 000047)
\$30,000

OSTLTS Partnerships CBA of the Public Health System
Task Force for Global Health, Inc. (OT13-1302, 000216)
\$354,508

Hawaii

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
University of Hawaii as a bona fide for American Samoa (DD11-1101, 000777)
\$139,333

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
University of Hawaii as a bona fide for Marshall Islands (DD11-1101, 000796)
\$81,568

Idaho

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Idaho Dept of Health and Welfare (DD11-1101, 000801)
\$57,019

Illinois

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Illinois Department of Public Health (DD10-1001, 000598)
\$200,000



Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Illinois Dept of Public Health (DD11-1101, 000825)
\$165,348

National Spina Bifida Patient Registry - Clinic Demonstration Project
Children's Memorial Hospital Chicago (DD11-001, 000744) *Use of carryover funds

Public Health Research for the Prevention of Complications of Bleeding Disorders
American Thrombosis and Hemostasis Network (DD11-009, 000761) *Use of carryover funds

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders
American Thrombosis and Hemostasis Network (DD14-1409, 000862)
\$3,952,289

Improving the Health of People with Disabilities through State Based Public Health Programs
Illinois State Department of Public Health (DD12-1204, 000938)
\$300,000

Blood Safety Surveillance Among People with Blood Disorders
Lurie Children's Hospital of Chicago (DD11-1108, 000872) **No FY 14 Funds – ended 4/30/14

OSTLTS Partnerships CBA of the Public Health System
AAP (OT13-1302, 000167)
\$1,222,678

Indiana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Indiana State Department of Health (DD11-1101, 000790)
\$152,691

National Spina Bifida Registry Longitudinal Data Collection and Evaluation
Indiana University- Riley Hospital for Children (DD11-005, 000769) **No FY 14 Funds – ended 9/29/14

Iowa

Utilizing Existing Birth Defects Surveillance Program to include Surveillance Data on Stillbirths
Iowa Department of Public Health (DD10-1007, 000730)
\$300,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs Iowa
Dept of Public Health (DD11-1101, 000785)
\$175,000



Centers for Birth Defects Research and Prevention
University of Iowa (DD09-001, 000492) **No FY 14 Funds – ended 8/30/14

MD STARnet: Feasibility of Expansion to other Muscular Dystrophies
University of Iowa (DD11-006, 000831) *Use of carryover funds

Improving the Health of People with Disabilities through State Based Public Health Programs
Iowa State Department of Public Health (DD12-1204, 000949)
\$300,000

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
University of Iowa (DD13-003, 001035)
\$745,000

Kentucky

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Kentucky Cabinet for Health & Family Services (DD10-1001, 000606)
\$179,936

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Kentucky Cabinet for Health and Family Services (DD11-1101, 000828)
\$161,365

Louisiana

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Louisiana Office of Public Health (DD10-1001, 000623)
\$185,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Louisiana Office of Public Health (DD11-1101, 000841)
\$162,446

Maine

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs - Non-Research
Maine Department of Health (DD11-1101, 000813)
\$122,924



Maryland

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II

Johns Hopkins University School of Public Health (DD11-002, 000746)

\$1,691,706

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Maryland Department of Health and Mental Hygiene (DD11-1101, 000782)

\$116,076

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network

Johns Hopkins University (DD10-1002, 000675)

\$279,470

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome

CHADD, Inc. (Children & Adults with Attention Deficit Hyperactivity Disorder) (DD13-1302, 001049)

\$800,000

OSTLTS Partnerships CBA of the Public Health System

Association of University Centers//Disabilities (OT13-1302, 000140)

\$1,033,778

Evaluation of Health Promotion & Prevention Program for Blood Disorders

National Blood Clot Alliance (DD14-1405, 001153)

\$180,175

Massachusetts

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs

Commonwealth of Massachusetts Department of Public Health (DD11-1101, 000783)

\$146,823

Birth Defects - Risk Factors for Folic Acid-Resistance Spina Bifida

Boston University Medical Campus (DD10-002, 000697)

\$244,902 (includes \$196,109 original award with a 25% supplement of \$48,793)

Improving the Health of People with Disabilities through State Based Public Health Programs

Massachusetts State Department of Public Health (DD12-1204, 000940)

\$300,000

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults

Massachusetts State Department of Public Health (DD12-1207- 001029)

\$425,000



Disabilities Improving the Health of People with Disabilities through State Based Public Health Programs
University of Massachusetts Medical School Worcester (DD12-003, 000914)
\$198,928

Birth Defects Study To Evaluate Pregnancy Exposed (BD-STEPS)
Massachusetts State Department of Public Health (DD13-003, 001037)
\$765,000

Michigan

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research
Michigan Department of Community Health (DD10-1001, 000615)
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Michigan Department of Community Health (DD11-1101, 000798)
\$174,500

Data Coordinating Center for Autism and Other Developmental Disabilities Research and Epidemiologic Studies
Michigan State University (DD12-001, 000901)
850,000

National Spina Bifida Patient Registry - Clinic Demonstration Project
Wayne State University (DD11-001, 000740) **No FY 14 Funds project ended 8/31/14

Blood Safety Surveillance Among People with Blood Disorders
Michigan Department of Community Health (DD11-1108, 000876) **No FY 14 Funds project ended 4/30/14

Improving the Health of People with Disabilities through State Based Public Health Programs
Michigan State Department of Community Health (DD12-1204, 000930)
\$300,000

Minnesota

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research
Minnesota Department of Health (DD10-1001, 000594)
\$175,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Minnesota Department of Health (DD11-1101, 000842)
\$121,309



Mississippi

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Mississippi Department of Health (DD11-1101, 000820)
\$116,032

Blood Safety Surveillance Among People with Blood Disorders
University of Mississippi Medical Center (DD11-1108, 000879) **No FY 14 Funds project ended 8/31/14

Hemoglobinopathies Surveillance, Health Promotion and Laboratory Capacity Demonstration Project
Mississippi Department of Health DD14-1408 - (DD1-1206, 001011)
\$100,000

Missouri

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Missouri Dept of Health and Senior Services (DD11-1101, 000815)
\$89,607

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
Washington University (DD10-1002, 000684)
\$6,340

Fetal Alcohol Spectrum Disorders Regional Training Centers
Saint Louis University (DD11-1107, 000884) **No FY 14 Funds project ended 9/29/14

Montana

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Montana Department of Public Health and Human Services (DD11-1101, 000811)
\$154,182

Improving the Health of People with Disabilities through State Based Public Health Programs
Montana State Department of Public Health (DD12-1204, 000991)
\$300,000

Nebraska

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Nebraska Department of Health & Human Services (DD11-1101, 000797)
\$107,104



Nevada

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Nevada Department of Health and Human Services (DD11-1101, 000788)
\$123,425

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Board of Regents, University of Nevada Reno (DD11-1107, 000888)
\$75,000

Fetal Alcohol Spectrum Disorders Regional Training Centers
University of Nevada at Reno (DD14-1402, 001132)
275,000

New Hampshire

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
New Hampshire Birth Conditions Program (DD10-1001, 000607)
\$160,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
New Hampshire Department of Health and Human Services (DD11-1101, 000827)
\$132,496

Improving the Health of People with Disabilities through State Based Public Health Programs
University of New Hampshire (DD12-1204, 000954)
\$300,000

Reducing Health Disparities among People with Intellectual Disabilities
University of New Hampshire (DD12-003, 000917)
\$249,736

New Jersey

Birth Defects - Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs - Non-Research
New Jersey Department of Health and Senior Services (DD10-1001, 000599)
\$200,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
New Jersey Department of Health and Senior Services (DD11-1101, 000805)
\$170,048

National Public Health Practice and Information Center on Paralysis
Christopher Reeve Paralysis Foundation (DD11-1102, 000838) **No FY 14 Funds – project ended 5/31/2014



Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network
University of Medicine and Dentistry of New Jersey (DD10-1002, 000674)
\$108,755

New Mexico

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
New Mexico Department Of Health (DD11-1101, 000807)
\$106,111

New York

Centers for Birth Defects Research and Prevention -
NYS Health Research, Inc/New York State Department of Health (DD09-001, 000487) **No FY 14 Funds – project ended 8/30/14

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Health Research Inc/NYS Dept of Health (DD11-1101, 000795)
\$156,338

Promoting Health of Individuals with Clotting Disorders
National Blood Clot Alliance (DD09-904, 000545) **No FY 14 Funds – project ended 9/29/2014

Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach
National Hemophilia Foundation (DD09-905, 000534) **No FY 14 Funds – project ended 9/29/14

Evaluation of Health Promotion and Prevention programs for Blood Disorders
Cooley's Anemia Foundation.(DD14-1405)
\$150,000

Evaluation of Health Promotion and Prevention programs for Blood Disorders
National Hemophilia Foundation (DD14-1405)
\$460,655

Evaluation of Health Promotion and Prevention programs for Blood Disorders
National Blood Clot Alliance. (DD14-1405)
\$180,175

Surveillance of Fetal Alcohol Syndrome Utilizing the Infrastructure of Existing Surveillance Programs –
NYS Health Research, Inc/New York State Department of Health (DD09-910, 000532) **No FY 14 Funds – ended 9/29/14

Reducing Risks for Alcohol Exposed Pregnancy in Women attending Federally-Funded Community Health Centers
NYC Health and Hospital Corp (DD10-1006, 000728) **No FY 14 Funds - ended 8/31/2014



MD STARnet: Feasibility of Expansion to other Muscular Dystrophies
Health Research Inc/NYS Dept of Health (DD11-006, 000836) *Use of carryover funds

Pilot Longitudinal Data Collection to Inform Public Health – Fragile X Syndrome
Research Foundation for Mental Hygiene, Inc. (DD11-007, 000753)
\$664,820

Improving the Health of People with Disabilities through State Based Public Health Programs
New York State Department of Health (DD12-1204, 000937)
\$300,000

Surveillance of Congenital Heart Defects (CHDS) Focusing on Adolescents and Adults
New York State Department of Health (DD12-1207- 001017)
\$400,000

Evaluation of Treatments and Services Provided to People with Duchenne Muscular Dystrophy (DMD)
Center of Environmental Health (DD13-002, 001041)
\$250,000

Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)
Health Research Inc./NYSDOH-Center for Environmental Health (DD13-003, 001032)
\$765,000

National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity
Disorder or Tourette Syndrome
Tourette Syndrome Association, Inc (DD13-1302, 001050)
\$800,000

OSTLTS Partnerships CBA of the Public Health System
March of Dimes Birth Defects Foundation (OT13-1302, 000199)
\$1,444,001

North Carolina

Birth Defects - Centers for Birth Defects Research and Prevention - Research
University of North Carolina-Chapel Hill (DD09-001, 000488) **No FY 14 Funds –ended 8/30/14

Birth Defects - The North Carolina Cleft Outcomes Study - Research
University of North Carolina-Chapel Hill (DD10-001, 000696) *Use of carryover funds

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
North Carolina Department Of Health And Human Services (DD11-1101, 000823)
\$162,203

National Spina Bifida Patient Registry - Clinic Demonstration Project
Duke University (DD11-001, 000742)
\$47,077



Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II
University of North Carolina at Chapel Hill (DD11-002, 000749)
\$1,100,000

Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting Disorders
Duke University (DD14-1409, 000860)
\$190,000

Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism
Duke University (DD14-1407, 000897)
\$150,000

Improving the Health of People with Disabilities through State Based Public Health Programs
North Carolina State Dept of Health & Human Services (DD12-1204, 000952)
\$300,000

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM) Network
University of North Carolina – Chapel Hill (DD10-1002, 000687)
\$290,841

Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)
University of North Carolina at Chapel Hill (DD13-003, 001036)
\$765,000

Promoting Health of Individuals with Clotting Disorders
Duke University (DD09-904, 000553) ** No FY 14 Funds – project ended 9/29/14

Comp B- Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders
Research Triangle Institute (DD14-001, 1116)
\$416,942

Comp B- Natl SB Patient Registry and Urologic Management of Young Children with SB
Duke University (DD14-002, 1082)
\$59,720

Public Health Surv of Deep Vein Thrombosis
Duke University (DD14-1407, 000897)
\$150,000

PH Surv for the Prev of Complications of Blood Disorders
Duke University (DD14-1409, 000860)
\$190,000



North Dakota

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
North Dakota - Minot State University (DD11-1101, 000802)
\$155,703

Improving the Health of People with Disabilities through State Based Public Health Programs
Minot State University (DD12-1204, 000950)
\$300,000

Ohio

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Ohio Department of Health (DD10-1001, 000611)
\$180,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Ohio Department of Health (DD11-1101, 000804)
\$89,151

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Children's Hospital Medical Center (DD11-005, 000766) **No FY 14 Funds –ended 6/29/14

National Spina Bifida Patient Registry - Clinic Demonstration Project
The Research Institute at Nationwide Children's Hospital (DD11-001, 000738) **No FY 14 Funds –ended 8/3/14

Improving the Health of People with Disabilities through State Based Public Health Programs
Ohio State Department of Health (DD12-1204, 000931)
\$300,000

Oklahoma

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Oklahoma Department of Health (DD10-1001, 000595)
\$185,000

Early Hearing Detection and Intervention Surveillance and Integration - Non-Research
Oklahoma State Department of Health (DD11-1101, 000814)
\$142,750

Public Health Surveillance of Deep Vein Thrombosis and Pulmonary Embolism
University of Oklahoma Health Sciences Center DD14-1407 (DD11-1109, 000899)
\$150,000



Oregon

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Oregon State Dept of Human Services (DD11-1101, 000799)
\$162,365

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Oregon Health & Science University (DD11-005, 000772) *Use of carryover funds

Improving the Health of People with Disabilities through State Based Public Health Programs
Oregon Health & Science University (DD12-1204, 000942)
\$300,000

Comp B- Oregon Spina Bifida Registry Project
Oregon Health & Science University (DD14-002, 001071)
\$60,999

Comp C- Urologic Protocol for Infants with Myelomeningocele
Oregon Health & Science University (DD14-002, 001058)
19,983

Pennsylvania

National Spina Bifida Patient Registry - Clinic Demonstration Project
Pennsylvania State University Hershey Medical Center (DD11-001, 000736) **No FY 14 Funds –ended
8/31/14

National Spina Bifida Patient Registry - Clinic Demonstration Project
University of Pittsburgh (DD11-001, 000737) **No FY 14 Funds- ended 8/31/14

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore
Early Development (SEED) II
University of Pennsylvania (DD11-002, 000752)
\$1,100,000

Improving FAS Disorder Prevention & Practice through Partnerships
University of Pittsburgh (DD14-1403, 001135)
\$243,538

Comp B- National SB Patient Registry
University of Pittsburgh (DD14-002, 001078)
\$59,985



Rhode Island

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Rhode Island Department of Health (DD10-1001, 000612)
\$160,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Rhode Island Department of Health (DD11-1101, 000791)
\$146,000

Improving the Health of People with Disabilities through State Based Public Health Programs
Rhode Island State Department of Health (DD12-1204, 000944)
\$300,000

Development and Evaluation of a Clinic-Based Screening and Brief Intervention (SBI) for Changing Behaviors
Related to CMV Transmission in Pregnant Women
Women and Infants' Hospital (DD12-005, 000921)
\$31,169

South Carolina

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
South Carolina Department of Health and Environmental Control (DD11-1101, 000779)
\$91,059

Pilot for State-specific Cross-Sectional Surveillance of Persons with Rare Disorders & Longitudinal Assessment
of Outcomes
South Carolina Research Foundation (DD11-004, 000776) *Use of carryover funds

Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other
Disabilities
University of South Carolina (DD12-006, 001007)
\$3,353,525

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through (ADDM)
Network
Medical University of South Carolina (DD10-1002, 000682)
\$142,758

A Pilot Surveillance System for High Impact/Low Prevalence Congenital and Inherited Conditions
University of South Carolina at Columbia (DD12-002, 000927) *Use of carryover funds

Improving the Health of People with Disabilities through State Based Public Health Programs
University of South Carolina at Columbia (DD12-1204, 000945)
\$299,930



South Dakota

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
South Dakota Department of Health (DD11-1101, 000794)
\$138,550

Tennessee

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Tennessee Department of Health (DD11-1101, 000786)
\$153,526

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Meharry Medical College (DD11-1107, 000882)
\$75,000

National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities
Amputee Coalition of America (DD12-1205, 000904)
\$2,100,000

Comp B. National SB Patient Registry at Vanderbilt Children's Hospital
Vanderbilt University Medical Center (DD14-002, 001073)
\$60,188

Texas

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Texas Department of State Health Services (DD11-1101, 000781)
\$136,688

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida
Baylor College of Medicine (DD14-002, 001072)
\$19,494

Comp C- National Spina Bifida Patient Registry/Urological Component
Baylor College of Medicine (DD14-002, 001070)
\$59,776

Utah

Centers for Birth Defects Research and Prevention
Utah State Department of Health (DD09-001, 000490) **No FY 14 Funds –ended 11/30/14



Public Health Research on Craniofacial Malformations Research
Utah State University (DD10-001, 000698)
\$250,000

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Utah State Department of Health (DD11-1101, 000821)
\$145,850

National Spina Bifida Patient Registry-Clinic Demonstration Project
IHC Health Services, Inc., Db: LDS Hospital (DD11-001, 000745)
\$40,871

Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network
University of Utah (DD10-1002, 000685) *Use of carryover funds

Comp B-Improving the Care and Outcomes of People Living with Spina Bifida
IHC Health Services, Inc. (DD14-002, 001062)
\$59,766

Comp C- National Spina Bifida Patient Registry/Urological Component
IHC Health Services, Inc. (DD14-002, 001060)
\$19,992

Vermont

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Vermont Department of Health (DD11-1101, 000818)
\$150,000

Virginia

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Virginia Department of Health (DD11-1101, 000812)
\$106,650

Craniofacial Malformations Information for Affected Families, Health Care Providers and School Professionals
Operation Smile (DD11-1105, 000868) **No FY 14 Funding – ended 6/30/14

Washington

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Washington State Department of Health (DD11-1101, 000800)
\$163,963



National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Seattle Children's Hospital (DD11-005, 000771)
\$70,000

Behavioral Risk Factor Surveillance System (BRFSS)
Washington State Department of Health (SO11-1101, 000047)
\$30,000

West Virginia

Wisconsin

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Wisconsin Department of Health and Family Services (DD11-1101, 000806)
\$165,000

Fetal Alcohol Spectrum Disorders (FASD) Regional Training Center
Board of Regents of the University of Wisconsin System (DD11-1107, 000885)
\$300,000

National Spina Bifida Registry Longitudinal Data Collection & Evaluation
Children's Hospital of Wisconsin (DD11-005, 000768) *Use of carryover funds

Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Developmental Disabilities
through ADDM Network
University of Wisconsin - Madison (DD10-1002, 000677)
\$272,395

Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native
Population thru Training & Technical Assistance
University of Wisconsin (DD13-1301, 001048)
\$275,000

Wyoming

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Wyoming Department of Health (DD11-1101, 000787)
\$141,924

District of Columbia

Preventing Complications of Persons with Hereditary Blood Disorders Through Health Education and Outreach
Hemophilia Federation of American (DD09-905, 000537) **No FY 14 Funds – ended 9/29/14



Enhanced Resources for FASD Prevention and Intervention thru National Networking, Education and Dissemination

National Organization on Fetal Alcohol Syndrome Prevention (DD10-1005, 000700) **No FY 14 Funds - ended 8/31/14

Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders
Hemophilia Federation of America (DD14-1409, 000859)
\$190,000

Evaluation of Health Promotion and Prevention programs for Blood Disorders Hemophilia Federation of America.
Hemophilia Federation of America (DD14-1405)
\$173,165

Improving the Health of People with Intellectual Disabilities
Special Olympics, Inc. (DD12-1201, 000995)
\$2,500,000

Improving Health of People with Intellectual Disabilities
ARC of the United States (DD12-1201, 000993)
\$1,000,000

Collaboration with Academia to Strengthen Public Health Workforce Capacity
American Assoc of College of Nurses (OE12-1201, 000003)
\$499,976

OSTLTS Partnerships CBA of the Public Health System
National Association of County City Health Officials (OT13-1302, 000172)
\$71,755

OSTLTS Partnerships CBA of the Public Health System
American Public Health Association (OT13-1302, 000131)
\$13,747

A Life Reliable Battery as Emergency Backup Power for Medical Devices
Bettergy Corp (PA13-234, 001053)
\$149,902

Puerto Rico

Population Based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs
Puerto Rico Department of Health (DD10-1001, 000600)
\$175,000



Guam

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
University of Guam (DD11-1101, 000784)
\$132,669

Commonwealth of the Northern Marianna Islands

Commonwealth of the Northern Marianna Islands
Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Commonwealth of the Northern Marianna Islands (DD11-1101, 000792)
\$122,545

Palau

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Republic of Palau Ministry of Health (DD11-1101, 000809)
\$93,175

Federated States of Micronesia (FSM)

Development, Maintenance & Enhancement of EHDI Info Systems (EHDI-IS) Surveillance Programs
Federated States of Micronesia Department of Health, Education and Social Affairs
(DD11-1101, 000778)
\$86,858

Beirut

Birth Defects - Surveillance of Birth Defects in Low and Middle Income Countries - Non Research
American University of Beirut (DD11-1104, 000843) **No FY 14 Funds – project ended 9/29/14

Switzerland

Global Prevention of Non-Communicable Disease Prevention & Promotion of Health
World Health Organization (GH1420)
\$895,075

China

Conducting Public Research in China
Chinese Center for Disease Control and Prevention (GH12-005, 000636)
\$50,000



India

Addressing Emerging Infectious Disease and Related Public Health
Concerns in India
National Centre for Disease Control (GH10-002, 000066)
\$40,000

South Africa

Project A – Birth Defects
Tanzania – Ministry of Health and Social Welfare (GH14-1418, 001247)
\$50,000

To view the annual report online, please visit:
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